



SPINAL COURIER

SPINAL CORD
COMMISSION

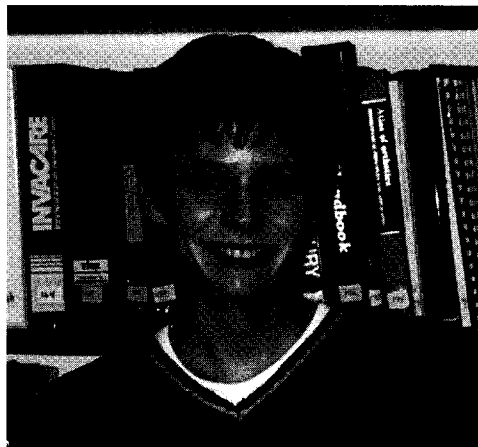
Vol. 10, No. 2

January 1999

ASCC Has a New VISTA Volunteer

It is always an exciting time when a new person comes to work at the Spinal Cord Commission, especially when that person is a Volunteers In Service To America (VISTA) volunteer. These VISTA volunteers spend their time working on specific projects at the Commission, building our capacity for new services and developing new projects and programs.

In October, we were delighted to welcome our newest volunteer, Kristie Soto, to the Commission. She serves as the Education and Resource Center Coordinator, so if you need any resource material, videos or other information, she would be happy to help you.



ASCC VISTA Volunteer Kristie Soto is the new coordinator of the McCluer Education and Resource Center on Spinal Cord Injury.

Kristie will also spend much of her time with ASCC translating

Spinal Cord Commission forms, fact sheets and informational brochures into Spanish for our increasing Hispanic population. Additionally, she will have the challenging task of coordinating ASCC's two regional miniconferences in 1999.

Kristie comes to ASCC from Wynne, AR, and has a Master of Arts degree in Sociology from Arkansas State University. North Texas University recently accepted her into their Ph.D. Sociology program, which she plans to begin later this year.

Please join us in welcoming Kristie to the Commission! ☺

Wintertime Poses Special Concerns

By Ben Hollis, SCI Coordinator, V.A. Medical Center, N. Little Rock, AR

On a cold winter's evening nothing is more enticing than to sit by an open fireplace or a warm wood burning stove, absorbing the warmth and chasing the winter chill. This seemingly tranquil setting is of special concern for individuals with impaired sensation due to the risk of damage to skin secondary to burning. This same condition also exists in all vehicles used in winter. Individuals should observe placement of their feet to assure they are away from heater ducts in all cars and trucks, as these also provide an opportunity for skin damage.

Wintertime increases the risk of fires in the home due to open

flames, furnaces and space heaters. To help ensure a safe home this winter, use this checklist to determine the fire risk in your home:

- Fireplaces have an appropriate spark screen and spark mat in place.
- Furnaces have been checked for safe operation.
- Fire extinguishers (ABC type, for all types of fires) are located in the kitchen and the bedroom.
- Smoke detectors and carbon monoxide detectors are located in the sleeping quarters of the home and are tested quarterly for battery strength and functioning.
- Space heaters should not be placed next to draperies and should not be used unattended.
- Lighter fluid, gasoline or diesel fuel **IS NOT USED** to start fires in wood stoves or fireplaces.
- In homes with fireplaces or wood/coal burning stoves, chimneys are cleaned and inspected annually.
- Fire drills are accomplished monthly in the home.
- An escape plan and a designated area outside the home to meet following evacuation is known by all family members.

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SPINAL COURIER

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Visit our website at:
www.state.ar.us/ascc

or e-mail us at:
ARKSCC@AOL.com

With Thanks

ASCC accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at (501) 296-1788 / 1-800-459-1517 / TDD (501) 296-1794, or send your donation to:

AR Spinal Cord Commission
1501 North University
Suite 470
Little Rock, AR 72207

Donations this quarter from:

*John and Kitty Allen
Danny and Kim McBride*

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Resource Advisory Committee

Dear Editor:

I would like to ask *Spinal Courier* readers: Do you have internet access? Like to surf the Web? ASCC is recruiting volunteer members for a Resource Advisory Committee (RAC). RAC members will:

- Evaluate the resources currently available on the ASCC website;
- Assist in developing a needs assessment for the site;
- Recommend changes and additions to improve the site.

RAC meetings will be held at the ASCC offices in Little Rock. However, persons who would like to be involved but cannot travel to

Little Rock may participate via conference call.

For more information about the Resource Advisory Committee, contact me at ASCC, 1501 North University, Suite 400, Little Rock, AR 72207; phone, **501-296-1792** or **1-800-458-1517**; or e-mail me at **ARKSCC@aol.com**. If contacting me by mail or e-mail, please include the following information about yourself: name, address, phone number, e-mail address, do you have easy access to the internet? do you utilize assistive technology when using a computer?

*Kristie Soto
VISTA Volunteer*

From the Director

Happy New Year! We're on the countdown now for the new millennium! Despite all of the scares about the computer glitches, and trying to remember to write 20 instead of 19 on checks and letters and such, I'm looking forward to it! When you think of all the things that happened in this century — it boggles the mind to think what the 21st century will bring! It surely gives us something to think about this year!

Over the years, many people have helped the Spinal Cord Commission in our mission to help those with spinal cord disabilities live independent lives. One of those people is Representative Dennis Young from Texarkana. Mr. Young has gone to bat for our Commission many times. He helped us expand our Long Term Attendant Care program in 1995 and this year he helped us again. We are disappointed to see him leaving the House of Representatives (one of those term limits folks) — we need consumer oriented people like him up there making decisions! Thanks, Mr. Young, we appreciate all you have done for persons with disabilities!

We bade farewell to another Commission supporter when Maurice Smith passed away in December. Mr. Smith's wife, Jane, is the "godmother" of our Commission and of SCI care in our state. Many of you are aware of her role or maybe have even benefitted directly from her work. While Jane had the vision and made all the plans, Maurice was the one who made things happen. Though he had many "bigger fish to fry" as the Governor's Chief of Staff, as Chairman and later Director of the Highway Commission and as a University of Arkansas Trustee, as well as his personal business, Maurice always found time to help Jane help people with spinal cord disabilities. His work, though seldom seen, had a huge impact for us and we will always be grateful.

Cheryl L. Vines

Hot Springs Rehabilitation Center: Pioneering Services to Persons with SCI

It was the first week in January 1961, when **Patricia Masingale**, a 19-year old with paraplegia from Benton, rolled into Hot Springs Rehabilitation Center (HSRC) in Hot Springs. "It was BIG," Pat recollected of her first thoughts. Little did she know that she was making history. While Pat was the first student to enroll at HSRC, 27,310 students have followed her over the past 37 years according to HSRC Administrator **Tim Milligan**, who expects many more as the Center continues to grow and develop to meet the needs of Arkansans with disabilities.

Pat Masingale had graduated from Benton High School and came to the Center to take a secretarial course. She describes the early weeks as quiet, with young women in the fifth floor dorm and young men on the fourth floor, sharing dorm parents. By the end of the year, Pat had obtained her secretarial course certificate and a marriage certificate. She and her husband John met and married during her time at the Center. They now live in Benton, have two adult children and three grandchildren. Ironically, in 1983, Pat put her HSRC training to work when she went to work in the Center's Counseling Department in the very same rooms where she had taken courses over 20 years before. She spent ten years at the Center before retiring in 1993.

Jess Helm remembers HSRC a little differently. Jess had lived with his SCI for nearly 10 years, had graduated from high school and was trying to gain admittance to the University of Arkansas when he first heard about the Center. He arrived in 1967 and learned a lot about ADLs and becoming independent. He took a "hiatus" when, on the recom-

mendation of then HSRC Medical Director Dr. **Shirley McCluer**, he received the first Harrington rods surgically implanted in Arkansas in 1968. After recuperating, he returned to the Center to study drafting. His social activities got him in trouble and he left HSRC. Jess, now a city planner for the City of North Little Rock, cites

going to the Center as the best thing that happened to him, followed closely by getting "dismissed" which made him think about what he had to do next. He decided to attend technical school in Camden and obtain a degree in Commercial Arts, which has served him well. Jess remembers meeting people at the Center from all over the U.S., both students and health care interns in P.T. and O.T. who came to train at HSRC.

There are, without a doubt, many other Arkansans with SCI and other disabilities who could share and compare their experiences at the Center over the years.

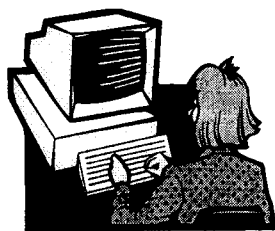
That "BIG" building on the hill behind bathhouse row in Hot Springs National Park was originally an Army-Navy hospital, first established on that site in 1860. When the federal government decided to close the facility after World War II, there was much discussion about what would become of it. The people at Arkansas Rehabilitation Services had a vision of how it could benefit Arkansans with disabilities and convinced the Governor to



lease the facility for \$1 a year to establish a state center for vocational rehabilitation and physical restoration. The rest is, as they say, history!

Today, the Hot Springs Rehabilitation Center provides a variety of rehabilitation services to nearly 1,000 individuals each year. Their CARF (Commission on Accreditation of Rehabilitation Facilities) accredited medical unit provides acute rehabilitation treatment to individuals with spinal cord and head injuries, strokes and orthopedic disabilities. According to a 1995 survey by ASCC, HSRC provides care to approximately 50 newly injured SCI's each year, more than all other Arkansas rehabilitation centers combined. Besides inpatient services, the Center provides outpatient services, including wheelchair and seating clinics, and a comprehensive SCI clinic.

The vocational program, soon to become the Arkansas Career Training Institute, offers courses in 28 areas of study, ranging from food service and personal
Continued on pg. 4 - see "HSRC"



Discussion List for Teens with Spina Bifida

SB-TEENS
is a new
e-mail

discussion list for teens with spina bifida. Currently there are approximately 25 subscribers who post messages to the list for all other subscribers to read. Topics that have been discussed so far include both spina bifida related and general "teen topics" such as dating, friends, music and self-esteem.

"SB-TEENS was created for teens with spina bifida to be able to meet on-line and exchange ideas, stories or just chat," says list co-moderator **Chuck Hurlburt**. Chuck is 35 years old and has spina bifida. **Carrie Bloss**, a 16-year old high school sophomore with spina bifida, is the other co-moderator. Carrie is developing a web page for the list with lots of links to other web sites of

interest to teens as well as sites relating to spina bifida. Anyone between the ages of 13 and 19 with spina bifida and their teenage siblings are welcome. "It is just a fun place on the net to converse with other people who know what you are going through," says Carrie.

To subscribe to SB-TEENS go to the web address: <http://sbteens.8m.com> and click on the "subscribe" button. You will then receive a confirmation letter, which you simply send back without changing anything by clicking on the "reply" button in your e-mail program. Make sure to send the message back word for word.

*Reprinted with permission from
Insights Into Spina Bifida, Nov./
Dec. 1998, page 12. &*

SBAA 1999-2000 Scholarship Fund

Applications for the 1999-2000 Scholarship Fund are available at Spina Bifida Association of America (SBAA). Last year SBAA disbursed \$10,000 in funds for college students. All students who are members of an SBA Chapter or SBAA are encouraged to apply.

The deadline for applications is **April 1, 1999**. Please send a self-address stamped envelope to:

Scholarship Committee
c/o SBAA
4590 MacArthur Blvd. NW,
Suite 250
Washington, DC 20007 &

Congratulations, Grant!



Grant Marshall of Magnolia, AR, was recently selected to serve a three-year term on the Southern Arkansas University Alumni Association Board. Other honors he has earned include being chosen as a member of the National Nominating Committee for the 1998 Outstanding Young Men of America and having been named as an Outstanding Young Man of America.

HSRC

Continued from page 3

care assistance to cosmetology, business, printing and auto mechanics. In addition, through a cooperative agreement with Garland County Community College, many students receive their Associate of Arts degree during their time at HSRC. The Center provides personal care support for individuals with tetraplegia to allow them to complete their vocational programs at the Center.

Serving our state's most severely disabled citizens, the Center has a graduation rate of about 100 students a year, with over a third of graduates going to a job immediately after graduation. As Jess Helm learned long ago, in addition to learning vocational skills, HSRC students learn "life skills" that help them in their personal as well as their vocational endeavors. For many, as it was for Pat Masin-

gale, it is their first time away from home and their first step to living independently.

Nearly forty years into their mission and faced with the new millennium, the Center is timeless. Inside the old marble walls and halls and up the staff-driven elevators, the latest technology is used to optimize the skills of the students who continue to come to the Center from all over the state. Milligan describes HSRC's vision for the future in expanding services to ventilator-dependent students, improving job placement and assisting in the transition from rehabilitation and training to independent living. Lofty aspirations? Not for a staff that has helped Arkansas' most severely disabled citizens return to independent living and jobs for the past 38 years — they're just getting started! &

Viagra and Its Use in Spinal Cord Injury

By Tom Kiser, M.D., ASCC Medical Director, and Scott A. MacDiarmid, M.D.

Viagra (*Sildenafil Citrate*) is a hot topic in the media and lay press — an effective pill to help men with erectile dysfunction is big news. Originally designed by Pfizer to prevent chest pain, Viagra did not work well. However, the side effect of penile erection was discovered when the patients in the original studies did not return the medication when requested. The rest is history.

Viagra works by increasing blood flow to the penis. It affects *nitrous oxide* (NO) in the corpus cavernosum (where the blood collects to make the penis rigid). With stimulation of the penis, NO activates the enzyme *guanylate cyclase*. This results in an increase in *cyclic guanosine monophosphate* (cGMP), which results in smooth muscle relaxation in the corpus cavernosum and allows the inflow of blood. Viagra inhibits the *phosphodiesterase type 5* (PDE5) of cGMP, which is responsible for the breakdown of cGMP in the corpus cavernosum. PDE5 is specifically present in the corpus cavernosum and vascular smooth muscle. Therefore with sexual stimulation and the release of NO, inhibition of PDE5 leads to increased levels of cGMP in the corpus cavernosum, resulting in prolonged smooth muscle relaxation and inflow of blood into the corpus cavernosum and a sustained erection. **It is important to note that Viagra does not increase normal erections, and it does not affect libido.**

Approximately 70% of men with impotence have responded favorably, and approximately 80% of spinal cord injured men responded well to Viagra. In the initial clinical trials by Pfizer, 83% of men with spinal cord injury (SCI) reported improved erections versus 12% on placebo, with 59% reporting successful intercourse

compared to 13% on placebo. A rigorous scientific study has not been conducted on individuals with SCI at the present time. We also do not know if individuals with a complete or incomplete lesion respond differently or if a quadriplegic responds differently from a paraplegic. It is expected that further research will be conducted in the near future.

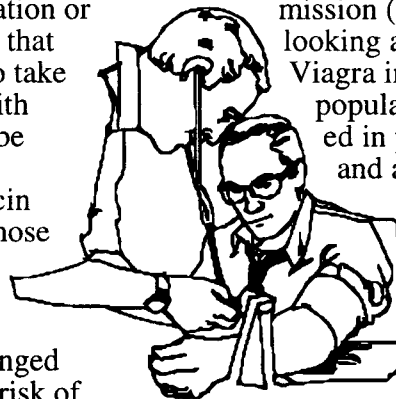
Anecdotally, one individual who used the medication in our clinic reported a good erection, but complained that it did not help him ejaculate. **Viagra is only able to help you get an erection and maintain it longer—it does not help with ejaculation.** It provides no protection measures to guard against sexually transmitted diseases such as gonorrhea or AIDS. There is no effect noted on sperm motility and morphology.

Viagra is contraindicated in individuals using nitrate medication, because it will cause a dramatic drop in blood pressure and has resulted in several deaths. **It is very important for all patients to check with their physician** to make certain they are not on any nitrate medication or other medications that may be harmful to take simultaneously with Viagra. It should be avoided in people taking erythromycin or cimetidine or those with liver or kidney disease since the half-life of Viagra is prolonged and increases the risk of problems. Viagra should be used with caution in individuals with chest pain, heart failure with hypotension and people on multiple drugs for high blood pressure. Also, people who use Viagra limit the options a doctor has in treating an individual if he has a heart

attack because nitrates can not be used for 24 hours after Viagra is taken. So, **if you have high blood pressure or heart disease you want to think twice before using Viagra**, because the risks are high.

Start with a 25 mg dose of Viagra, and slowly increase the dose to a maximum of 100 mg. The side effect profile markedly increases at doses greater than 100 mg with little or any benefit of improved erections noted. A small number of individuals with SCI may develop prolonged erections lasting more than an hour and a half but there have been no serious problems. If this occurs you should inform your physician and he will most likely lower the dose. The major side effects are headache (16%), flushing (10%) and disturbed digestion (7%). Abnormal vision, a blue haze, was noted in 3% of subjects and is felt to be secondary to cross-reaction with the PDE6 of cGMP which is present in the retina of the eye. The abnormal vision, however, is mild and transient.

The Arkansas Spinal Cord Commission (ASCC) is interested in looking at the benefit of using Viagra in the spinal cord injury population. If you are interested in participating in a study and are willing to be randomly placed in either the placebo or the Viagra study group, call ASCC at 501-296-1788 or 1-800-459-1517. You must be willing to have a physical exam, keep a diary and send in routine answers to questions. When you call, please leave your name, address and how you can be contacted. If there is enough interest, hopefully we can start a study in the next six to nine months. &



Wishes Can Come True !



Cardinals slugger Mark McGwire stands next to Frank Davila outside the Cardinals clubhouse at Busch Stadium in St. Louis, Missouri.

Frank Davila of Hot Springs has been a fan of **Mark McGwire** since 1988. In fact, Frank's living room can be called a Mark McGwire shrine, with photos, memorabilia, newspaper clippings and his prized collection of McGwire rookie baseball cards. Frank has something that few other fans can boast of — an official bat handed to him by McGwire himself on May 16, 1998, when his wish to meet Mark McGwire came true.

Frank's mother had written the *Make a Wish Foundation*, a non-profit organization that grants wishes to terminally ill or disabled people, explaining Frank's dream of meeting Mark McGwire. The foundation provided Frank with air transportation, lodging and stadium tickets to see the Cardinals play the Florida Marlins on May 15 and 16.

"I am one of the lucky ones," Frank said about his big day.

Mitrofanoff Procedure

By David B. Joseph, M.D., Professor of Surgery, University of Alabama at Birmingham; Chief of Pediatric Urology, Children's Hospital, Birmingham, AL

For some children who participate in self-catheterization (and for some caretakers), catheterizing through the normal urethral opening can be difficult. Alternatives are possible. We generally call the operation a Mitrofanoff procedure, named after the individual who first described using different "tubes," which allow the urinary bladder to be catheterized from the abdomen. The most common tube used is the appendix.

This provides a very natural conduit to catheterize and can be separated from the GI system without a change in bowel habit. If the appendix is unavailable, other tissue sources can be used such as the ureter, small bowel and bladder. Placing the "tube" into the belly button has become popular because you can hide the end of the tube you catheterize. But some children prefer having the end placed lower and to the side, which can also be done.

Bathing and swimming are not a problem. The most common problem with these "tubes" occurs with stenosis (scarring) at the skin level. The tubes can leak, but this isn't common. Other specific problems depend on the tissue used and additional procedures performed. This procedure can play a very important role in your child's independence and self-esteem. Talk with your pediatric urologist about options that would be appropriate for your child.

Reprinted with permission from Insights into Spina Bifida, Nov./Dec. 1998, page 3.

Clinical Practice Guidelines on Depression Following SCI Issued for Primary Care Providers

A new clinical practice guideline on treating individuals with depression following spinal cord injury is available from the Paralyzed Veterans of America on the organization's website at www.pva.org. It is available free of charge to medical professionals and the general public.

Depression Following Spinal Cord Injury: A Clinical Practice Guideline for Primary Care Physicians is intended for primary-care physicians and other health-care professionals when making clinical decisions regarding the treatment of depression

in individuals with spinal cord injury or dysfunction. The guideline offers treatment recommendations on assessment, diagnosis and psychological issues arising from depression. It also provides information on environmental and societal factors, social support systems, consumer and family education and evaluation and modification of treatment plans.

Health-care professionals may order a free copy of the depression clinical practice guideline by calling the PVA Distribution Center toll-free at 1-888-860-7244.

CM101: The Latest in the Search for a Cure

A new drug being tested against cancer has shown promise in the treatment of spinal cord injuries. According to researchers at Vanderbilt University, paralyzed mice regained the ability to walk after being treated with the experimental drug CM101.

The study design consisted of an experimental group, which received CM101, and a control group, which received no treatment. In the experimental group, 26 paralyzed mice were given CM101 within one hour of injury and five additional doses of the drug every other day. Within 12 days, 24 mice had regained the ability to walk, one mouse remained paralyzed, and one mouse died. In the control group,



14 paralyzed mice were not treated with the drug. Eight of the mice died, and the other six remained paralyzed.

The drug was being tested as an anti-cancer compound by Vanderbilt University because of its proven ability to prevent blood vessel growth, which is the method through which tumors survive and grow. In the case of paralysis, researchers believe that the blockage of new vessel growth by CM101 prevents the formation of scar tissue in the spinal cord, allowing severed nerve cells to reconnect.

While researchers are hopeful that the drug will have the same effect in humans, they remain cautious. Numerous other drugs tested have worked well in animals with limited or no effect on people with spinal cord injuries. Vanderbilt plans to begin testing CM101 on humans some time [in 1999].

If the drug is proven effective in humans, persons with newer spinal cord injuries would be the first targeted for its application.

Use of CM101 in persons with older injuries would first require surgery to remove scar tissue formed at the site of the injury. Then, other drugs would be needed to encourage nerve cell regrowth.

--- source: 10-26-98 CNN News web site, <http://cnn.com/HEALTH/9810/26/spinal.drug/index.html> ♪

Rollin' Razorbacks Tournament

The Arkansas Rollin' Razorbacks began the season undefeated after sweeping the Music City Invitational Tournament on Nov. 13-14, 1998, in Nashville, TN. The Razorbacks defeated the University of Illinois 51-29, the University of Wisconsin-Whitewater 77-41 and Music City Nashville 68-59.

The next tournament is scheduled for **Jan. 23-24, 1999**, at Sylvan Hills High School in Sherwood, AR.

Multiple Sclerosis Wellness Guide

The Paralyzed Veterans of America (PVA) Research and Education Program has published an informational guide for individuals with multiple sclerosis (MS), emphasizing how those with the disease can lead full lives.

Entitled *Multiple Sclerosis: A Self-Care Guide to Wellness*, the 150-page book informs patients and families about how MS affects the lives of both those with the disease and those who provide care. "This MS guide emphasizes that wellness can be achieved through education and commitment," stated Kenneth C. Huber, former PVA national president. "For those presently affected, there are treatments available

that reduce the severity of the disease and slow its progression. This guide outlines some of these treatments."

Traditionally, education about multiple sclerosis was medically oriented and slanted toward the consequences of the disease and the resulting dysfunction. "PVA's guide is different in that the contributors have concentrated on wellness, which is critical during this period of managed care and the increasingly difficult access to medical services," Huber stated. "The guide covers a broad spectrum of topics related to MS and its implication. Practical tips on self-care are designed to promote maximum independence, well-

being and productivity. Contributors to the guide are professionals who have a specialty or special interest in multiple sclerosis. Their suggestions, advice and strategies come from years of experience in the field. It is the hope of PVA and those contributors to this important book, that after reading this guide, those with MS will come away with fresh ideas on how to cope with the disease," Huber added.

Copies of *Multiple Sclerosis: A Self-Care Guide to Wellness* are available for \$9 by calling the PVA Distribution Center at **1-888-860-7244**, or by sending your request to P.O. Box 753, Waldorf, MD 20604-0753. ♪

New Resources In the Education and Resource Center

The McCluer Education and Resource Center has added several new items to its collection during the last few months. Our new resources include the following videos and books:

- **The Catastrophic Care Specialists — The Shepherd Center** video contains a tour of the Shepherd Spinal Center facility in Atlanta, Georgia, as well as a short description of the services offered.
- **The Hot Springs Rehabilitation** video offers a detailed look at the facilities and services provided.

- **The Adapted Driving School at the Shepherd Center** video provides an inside look at what is involved in the driving program offered through the Atlanta facility. A good resource for those considering taking a driving course.

- **Legal Rights of the Catastrophically Ill and Injured: A Family Guide, 2nd ed.** by Joseph L. Romano contains an explanation of legal rights and benefits a family can expect after the illness or injury of a loved one. It includes discussion about guardianship, insurance benefits, government-

tal programs and benefits, workman's compensation, and more.

- **The Stress Management Handbook** by Lori Leyden-Rubenstein describes in detail what stress is, how it arises, how it affects us, how to relieve stress, and how to overcome panic attacks.

If you are interested in checking out any of these resources, or if you are interested in finding information about other topics, please contact the Resource Center at **501-296-1792** or **1-800-459-1517**. &

Correction:

IndependentChoices' telephone number was listed incorrectly in the October 1998 issue of *Spinal Courier*. The toll-free number for IndependentChoices should have read **1-888-682-0044**.

Wintertime Concerns

Continued from page 1

- A mechanics creeper can assist disabled individuals in emergency home evacuation since using a wheelchair places the individual's head directly in the smoke. The mechanics creeper permits the person to "surfboard" to safety.

If you answered "yes" to all ten items, your home is reasonably safe. If any item was answered "no," please make appropriate corrections to make your home a safer place to live. &

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